



***A Message From VOR's President and Executive Director***



We start this message sharing great sadness. We lost a good friend, our Treasurer, and member of our Board, Larry Innis on August 30. Larry died peacefully, with family by his side, in his home town of Bethalto, Illinois. Larry was hired by VOR as our federal legislative liaison, working on Capitol Hill.

Although he did not have a family member with intellectual disabilities or autism, Larry worked with the same intensity and compassion as the rest of us. He worked many years alongside our Government Affairs Director Tamie Hopp, and represented VOR on Capitol Hill alongside our Board member emeritus, legislative specialist and father, Peter Kinzler.

After Larry retired from that position, he joined our Board of Directors as a volunteer and served as Treasurer from late 2015 until his death last month. Larry spoke softly, with meaning and incite and always made the conversation better. He leaves a gigantic hole and is missed dearly.

If Larry were reading this, he would let us all know in his quiet way... to move on, because we still have work to do.

So, we'll continue... Last week, VOR's Executive Director Hugo Dwyer, and our Legislative Advisor Gayle Gerdes attended the two-day meeting of the President's Committee for People with Intellectual Disabilities (PCPID). We were given the status of "Public Observers", meaning that we were allowed to observe, but not allowed to speak or contribute in any meaningful manner. As many of our members know, The PCPID is facilitated by the Administration for Community Living (ACL). Members of the committee were selected from applicants by the Director of Disability Policy in the White House Domestic Policy Office. This term, the White House chose more self-advocates than ever before, resulting in a majority of members of the committee being self-advocates, all of whom receive services through the Home and Community Based-Services (HCBS) silo of CMS. No representatives had been chosen to speak on behalf of people who receive long-term services and supports through the "institutional" silo of Medicaid. The topic for this session was "Addressing Issues Surrounding Home- and Community-Based Services (HCBS)". The only references to people who rely on intermediate care facilities were emotional pleas to free them so they can live in "the community". One self-advocate actually called out VOR by name, saying that we are the organization that forces people into institutions, and calling us "The Voice of Unreasonableness".

Nonetheless, Hugo and Gayle were present at the meeting, and did network and interact with members of the PCPID, ACL, and members of agencies covering I/DA issues before and after the meetings and during breaks, in an effort to expand the horizons of members to realize there are hundreds of thousands of people who have not been given a voice.

Included in this issue of the Voice is VOR's open letter to the President and the PCPID.

This issue also features personal stories from two ordinary / extraordinary women - mothers of children with unique challenges. Rhonda Butler represents Evangeline and Rapides Parishes in the Louisiana State House of Representatives. Rhonda was instrumental in passing a bill providing dental care for people with I/DD in group homes in Louisiana, then leaped a more difficult hurdle and passed the same provisions for dental care for those living in ICFs. A new member to VOR, Jill Clayton is a retired health care attorney from Brooklyn, NY, whose daughter Abby ..... well, read for yourself. Jill and Abby tell it better.

As we have ended every message to you in the previous issues of the VOICE, the VOR Board is deeply grateful for all your gifts, and for your ongoing support of the VOR mission, for our families, and for our loved ones with I/DD and autism. VOR exists because of YOU and because of YOUR GENEROSITY! And so, we must ask again, that if you have the means, that as you plan your year-end charitable giving, that you will please consider a gift to VOR. Thank you!

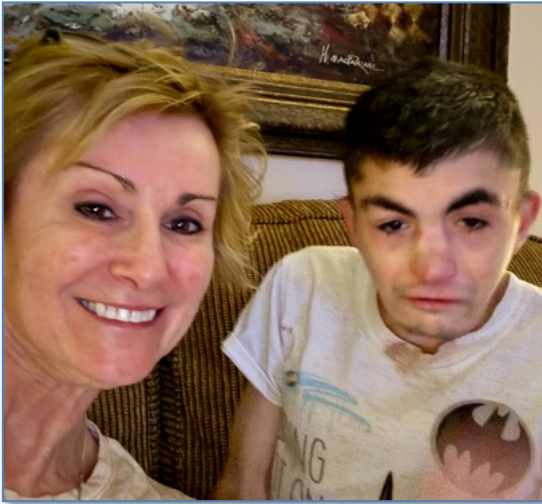
Most Sincerely,

Joanne St. Amand  
President, VOR Board of Directors

Hugo Dwyer,  
Executive Director of VOR – A Voice of Reason

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## My Name is Rhonda Butler and I Have a Special Needs Child Named Derek (Who we call Lil D)



I was asked to write this documentary about my life with my son and the journey that I've had through these 37 years. My first thoughts were, "How do I get that into a few pages? Hopefully I can share our challenges along with the bright light and wonderful experiences I have had with my son.

Let's start in the beginning, on December 3, 1987, at the age of 25 my first child was born at 1:05 PM, and needless to say he entered this world with a bang. Unlike most births I was given an emergency C-section because Derek had stopped moving. He'd been a very active baby, so we all knew something was wrong. We discovered that he had an obstruction to the small intestine and had to have surgery right away. After the birth he was shipped to Ochsner's Hospital in New Orleans. In the meantime, I had a reaction to the epidural and had to be intubated because I couldn't breathe. I was paralyzed for nine hours until I regained feeling back into my legs. The doctors discovered that from the obstruction the liquid surrounding Derek was infected. When they did the C-section, the infection entered my body causing me to run 105 fever for two days and basically kept me in a very ill state and sleeping. When I woke, I realized I

had a precious baby boy that was very ill, fighting for his life along with other issues.

I've always been a person to plan my life, how I wanted things to roll out. I planned my career, opening a business, building a home, the white picket fence, the marriage, but this I had not planned.

Fast forward 3 years. Not only did Derek survive, he thrived. It took lots of love, patience, heartbreak, and prayer daily to get through it all. God has always provided me with great medical teams, babysitters, friends and most importantly a wonderful loving family. I am forever grateful for all these people. Without them I could not have survived this. If Not for my faith and walk with God, I would've never made it. For the first year of Derek's life, he had nine surgeries and many life-threatening challenges after.

Also, what I didn't plan was a divorce, I don't know exactly what happened and what went wrong. Having a special needs child is not easy and not everyone can handle it. There are times you actually think things like, "I wish I didn't have a special needs child", "Why did this happen to me", and "I'm not sure I can get through it." But, In the back of your mind giving up is not an option. My mom has always told me you have a well of strength most don't possess, it will either make you or break you. Well Derek and I are still here and we're surviving. Without a doubt being Derek's mom has made me who I am today. He opened my eyes to love big, be humble, have patience, and see the world in a different way. He's shown me it's not about success, it's not about failure, it's not about being rich or poor and it is definitely not about race. Living with my son has let me know that God wants me to see these things the way my son sees them. That's fighting for, and giving a voice to, those who don't have one.

One of the most surprising moments in my life was when God put a man in my life that loved my son as much as he loved me. Someone that I have known since childhood we reconnected and were married. He told me that his experience of raising a special-needs child with me that has filled his heart with such grace and mercy. When I couldn't pick myself up, he did it for me. I think most people that meet me think or believe I can handle anything and that I have it all together. This is so far from the truth, I have days when I cry, days when I wanna give up. I have days when I don't speak to anyone and I become a recluse. It's just how I learn to deal with my life and issues I face with my son. You see I can't just go to the movies or go to dinner or go on vacations go to ball games or celebrate all the things most families do what we call normal families. Everything that I do has to be a planned out. Obviously, planning isn't a bad thing.

When Derek was about 11 years old, he started getting out of the house. He learned unlock the doors. I can't explain what that feeling is like when you lose your child and can't find them for over an hour. Derek also started self-injuring himself, because he has the mind of a one and a half-year-old. He would get knives or razors and cut himself, and worst of all he'd get in to any kind of medication we had in the home. He was very strong and could climb like no other. He was the size of a two-year-old and had the strength of a 10 year-old. After many self-injuries and hospital stays due to injuries, his almost choking to death, and the time he fell asleep in the dryer for two hours until we found him, I had to make a very hard decision, and began to look for a care facility for Derek to live in.

I remember how hard this was. I'll never forget it. Going and finding a place to put a child that's almost 12 years old that looks like a three-year-old in a facility that would become a Home was very hard for me to accept. In fact, I went and toured many of them, then came home and said no. As a mother you never are ever going to believe that anyone is going to take care of your child as well as you are.

Derek couldn't attend public school because they couldn't keep him in the classroom, he would get out and, let's be honest - he was just being babysat in school much like a daycare or at home. But Derek was self-injuring so often and getting out of the house and running off that I couldn't sleep at night. I had to make this choice. I had lost so much weight I looked anorexic. I had a full-time business to run I was running on 3 to 5 hours of sleep, seven days a week for 11 years and I was simply mentally and

physically exhausted. I hadn't been caring for myself, and Derek was regressing because I was hovering over him, and not allowing him to learn and to grow. I came to the realization that I was going to have to make the decision to place my son in a facility to help him and to help me. It took every ounce of faith that I had to get through it.

The doctor asked me had I ever heard of St. Mary's training school in Boyce Louisiana. He said that they had a school ground, they had a church, they had in-home living, and I could come get Derek whenever I wanted. They specialized in helping these children. I remember falling in love with the people there and what they provided and I had to realize in reality nothing's perfect and that if I was going to place my son here, I had to be involved in the school as well. I made the decision to do so and I can tell you it felt like a death. I felt like I abandoned my child that I was a horrible mother a horrible parent and a horrible person.

But you have to remember Derek was my only child and there was no one else if something happened to me who could care for him full-time like I did. My husband had two other children that he had to see about and he had a full-time job there were no other brothers and sisters that could come to his rescue. I remember that day leaving Saint Mary's and praying to Jesus for peace give me peace and tell me what I'm doing is the right thing. I can remember crying all night waking up and crying all night and my husband saying just go get him and bring him home I can't see you go through this. I would go and get on my knees and pray to God and ask him to show me the way and give me peace and then I would get peace and I would cry anyway.

Fast forward 25 years later my son is still at Saint Mary's. I had joined the PTA right away and got involved to make sure that we stayed on top of any issues that came up. One thing I have learned is if you want to fix problems you have to be a part of solution. I was a part of fundraising team and I got involved with the caretakers that loved him and took care of my son on a daily basis and I still do that to this day.

Is everything perfect? No, it isn't. Life is not perfect. We have issues every day we face from our business or with our other children, or just life in general. At St. Mary's I saw many issues faced with children and adults of special needs. Healthcare was a big issue. Finding funding sources for them to have the simple everyday things they need in life. Dental care and check-ups. Caretaker pay and more. In addition to being a part of St. Mary's group, I was also involved in community service. I worked on a team of women that we provided a festival for our community to provide funding in parks for our kids. I also was on the board of tourism for Evangeline Parish where I work on economic development and prospering are small rural communities. From there I was asked to sit on nonprofit foundations, advisory boards and other PTAs. What I didn't realize, all of these boards and servant positions poised to me for an opportunity that I did not plan.



I was approached by a very good friend in 2019 asking me to run for state representative for District 38 for the state of Louisiana. I immediately turned it down I said I cannot do this job I wouldn't know where to start and I walked away from the idea. I was approached twice more which I turned down, and decided to come home and discuss with my husband what I have been asked to do. My husband being who he is and so supportive and uplifting said this is a perfect job for you this is a servant job this is what you do and what you're good at. In the back of my mind, I'm thinking I can't do this. I don't have a college degree. I don't have any money, and I don't even know where to start. I have a special needs son and a business and there's no way I can pull this off. My husband said this is your God-given purpose. This is something you did not plan, you did not expect. This is how God does things.

I remember so clearly saying well it has to be a God thing because I'm broke. I don't even know where to start and if he wants me in this position he's gonna have to drop it on my head. Before I knew it I had \$10,000 in an account. I had a team of people surrounding me putting up signs and helping me hit the road to politic people I didn't even know, who believed in me for some reason that I couldn't see. In 2019 I won by 62% of the vote against two other opponents. Now that's a God thing.

I quickly realized the position I had taken was very serious and I had a lot of work to do. We weren't in session probably my first year in 2020 when Covid hit, we lost staff and even one of our colleagues to Covid. Special needs children and adults were put in a very serious position they were in lockdown parents were crying out and cannot see their children. Motherly instinct kicked in and immediately I passed a resolution to allow parents to go and get their children from these facilities and bring them home and keep them and not be charged a day rate, and if they wanted to bring the children back, they could be Covid-tested on the grounds before entering into the homes. It was my first resolution on the floor. I received a standing ovation from my testimony that I gave based off my own son and the heartfelt need to see him and put my hands on him. There wasn't a "No" vote in the house or the senate. That house resolution gave parents the ability to go and get their children. As I look back, I realize that was defining moment in my life in that house of representatives that make people know who I was and what I stand for. I am now known for the representative to protect special needs and fights for them and gives them a voice. What was shocking to me it's probably 90% of people in the house and the senate had no idea of what it was like to have a special needs child. I know that they were directly or indirectly affected by special-needs but they never really thought how hard it was in the struggles that we had. I am constantly told that if it weren't for me they had no idea that things were the way they were.

*(Continued on page 6)*



# Why I Am Very Tired: Our Family's Journey Through the American Behavioral Health System

By Jill Clayton

Our daughter Abby turned 29 in July of this year. She currently carries a long list of diagnoses, medical and other. She is on the autism spectrum. She has various psychiatric diagnoses, which change over time depending on who is assessing her and who is treating her. She also has a number of complex medical problems, including an autoimmune disorder and a metabolic disorder. The sheer variety of illnesses she has been diagnosed with over the years is staggering all by itself, but it is only one small measure of the grinding burden she has carried since birth. Despite all that, she is warm, sweet, and intermittently remains hopeful about her future.

Abby's saga started a few months after birth. In her first year of life, there were subtle but worrying signs that not all was well. She achieved certain developmental milestones right on time. Other milestones were delayed. Thanks to a kind and attentive pediatrician, our daughter was enrolled in an early intervention program by the age of 15 months, for speech and neuromuscular delays. That was only the beginning of our decades-long quest for help with her disabling neurodevelopmental and psychiatric symptoms. I am thankful now that I did know then just how exhausting and wrenching this quest would prove to be.

Abby started school with neurotypical children, then progressed to resource-intensive inclusion classes and then to a series of non-public day and residential schools for children with developmental and psychiatric disorders. The psychiatric hospitalizations started when she was eight years old. There have been 20 hospitalizations since that first one, some long, some short. In between all of this, Abby managed to finish high school at a specialized school for students on the autism spectrum. She had and has a dream of becoming an animal photographer.



Abby has had periods of relative stability, including one heady period for a few years after high school when she was traveling on her own on the subway to visit friends and family, and even traveling with a friend by air to visit his family in Georgia. By and large, though, Abby fell off the “autism services cliff” when she left high school. Because there is no federal mandate to provide supportive services after young adults leave school, the patchwork of community programs is just that – a patchwork, which is full of gaping holes.

The system of services for adults with behavioral health and developmental disorders is difficult to access, difficult to navigate, and mostly inadequate for adults who present a complex mix of symptoms. What programs do exist are run in our state by two different agencies. One agency views its mission as providing essentially care-taking services for adults with intellectual disabilities. The programs run by that agency have failed to grapple with the current reality, in which autism diagnoses have exploded and many of their clients also have psychiatric diagnoses. The other agency is operating in a world in which the only mental illnesses they are “supposed” to be taking care of are illnesses like

chronic schizophrenia or bipolar disorder, without developmental overlays. We and our daughter have, unfortunately, been caught in the cross-fire between these agencies, each of which insists that patients like our daughter should be the other agency's responsibility.

I can't count the number of psychiatrists who have told us over the years that they don't “treat autism”. Those physicians are right, of course, in the sense that there is no known medication which will undo or eradicate a neurodevelopmental disorder like autism. They are entirely wrong, however, in the belief that it is not their professional responsibility to try to understand what the world looks like to a patient on the autism spectrum. They are also wrong that it is not their responsibility to try to understand how developmental differences interact with psychiatric illness to produce what amounts to a different kind of clinical problem that requires non-standard solutions.

Although we have had our share of impatient clinicians and treatment programs that were visibly irritated by the fact that they were “stuck” with having to treat our daughter, we have also have been blessed over the years by a number of kind and helpful clinicians. We were lucky enough to have had our daughter recently under the care of a program which specializes in adults on the autism spectrum who also have psychiatric illness. Our daughter is extremely anxious. Who wouldn't be anxious, in a world which is constantly presenting new and confusing social situations which she can't interpret accurately and doesn't understand the proper response for? Our daughter's anxiety was interpreted accurately in that specialized program, and she was treated with kindness and insight. She flourished under this benevolent regime, which gave us hope for the first time in years that she would stabilize in the community. Unfortunately, that program came to an end. We have been forced since then to recognize anew just how dysfunctional and underfunded the rest of the treatment landscape is.

*(Continued on page 6)*



## The World I Would Like to Live In

My name is Abigail Goldin. I am twenty-nine years old. My family home is in Brooklyn, NY, where I would like to be. But I have been living in hospitals for most of the last 6 years.

It is hard for me to write things down, so I asked my parents to help me explain my feelings in writing.

I have autism, and also have anxious and sad feelings. I have been hospitalized a lot to get help with my sadness. Some of the hospitalizations have been helpful, some have not.

It is hard to live in hospitals. When staff in hospitals are taking care of me, I would like them to understand things about my autism that make me anxious and upset. Sudden loud noises make me very anxious. Fire alarms and yelling make me anxious. Sensory toys and weighted blankets help me to calm down. Many hospitals I have been in will not let me use sensory toys or deep pressure to help me feel calm.

Last year, I drew a picture of how good the world could be if people understood how it feels to have autism. I used a lot of bright colors, which expressed how hopeful I was feeling then. Since then, I have often felt hopeless and sad because I am not living in a place where people love me and understand me.

I want to live in a place where I can see my family, my friends, and my dog every day. I love taking care of animals, and taking pictures of animals and nature. I want to be in a place where I can work on my photography skills.

I know I need services and support. I want help, so I can live outside a hospital and be happy and safe. I want to live my life the best way I can.





*(Continued from page 4)* We are once again struggling to get our daughter out of the hospital and into a community level of care, which is where she longs to be. There simply are no available programs that are designed, funded, or staffed to provide our daughter with an appropriate transition back to a less restrictive level of care. The typical response of the acute care hospital is to announce that its work is done, and then hand the patient the first parachute that comes to hand while pointing to the open door of the plane. We have been through this routine too many times to believe that the parachute will open as intended, or that the landing will be safe.

With apologies to Dr. Martin Luther King for borrowing his powerful rhetoric, I too have a dream. I have a dream that my daughter will one day be known for the content of her character, not for the alphabet soup of her diagnoses. I have a dream that treatment providers will meet her where she is, not where their diagnostic categories say she should be, and help her to stabilize for the longer term.

I have a dream that she will live in a world which will look past her deficits and struggles, seeing instead the strengths and gifts she has to offer. I have a dream that her generosity, kindness, humor, and warmth will be recognized and given their just due.

I also have a dream that our society will stop stigmatizing people who are visibly different, and will help them to live the best lives they can. I have a dream that politicians and government agencies will recognize that spending on good treatment programs is not money wasted, but money saved on the costs down the line of repairing broken lives when treatment is not available.

Are these dreams likely to end in disappointment? Maybe. But that does not excuse us from undertaking the struggle to realize them.



*(Continued from page 3)*

I fought for an education savings account (ESA) bill for autistic children, passed it through the house and senate, but it was eventually vetoed by Governor Edwards. (This year, I worked with a senator and we passed a new ESA bill and it was signed by Governor Landry.) I was also instrumental in helping pass a bill for pay for caretakers. The next year I passed a dental program, working with the Louisiana Dental Task Force which was initiated by the Voice of Reason and their very own Mary Kay Cowen. My first hurdle was to get it for the waiver program, and the following year I managed to include ICFs in the program.

I also had to face the pain taking reality of abuse and neglect. Covid spurred the highest audits on abuse and neglect. Ever. The facilities were in lock down, no one was in there auditing, and there was no oversight or accountability. I was receiving calls from parents throughout the state, I immediately brought in Health and Welfare to do surprise checks and to start revamping our accountability system to protect our most vulnerable, our children. I had a dear friend that had went into a facility with her son and he faced some abuse and because of those incidents I dug in and realized that the abuse was coming from lack of leadership. One thing I can tell you about leadership is without accountability it leads to a series of bad decisions, and left unchecked to bed or immoral behavior. No one is above the law and no one is above accountability. You cannot change the reality of it if you pretend you don't see it. I immediately went to work with the parents at Pinecrest and we have moved the needle forward we are very excited about the changes that were made in leadership oversight and definitely the help of the department of Louisiana health and welfare. Being Vice chairman of health and welfare has given me the oversight to make sure these changes are happening. One thing I've learned about state issues is it takes a while, but I will not give up in this next year I'll be working harder for the better of our children of special needs, whether it be waiver, in-care facility or community-based, or educational systems. I believe the best is yet to come.



Starting the second term in 2024, I have already begin addressing caretaker shortage, pay, training, accountability, and abuse and neglect laws. Our first year has been a little more challenging we have a new governor with all new department heads. They have been excellent to work with and very supportive of my work. We came into two special sessions and a regular session in 2024. I was put on appropriations, vice chair of health and welfare, agriculture, chairman of the rural caucus, and I sit on Governor Landry's council for disabilities. I know I have a lot of work ahead of me but I know one thing I could've never been put in this position if God didn't want me here. I believe with everything in me this is my purpose and it was for these children.

I would not change my child for the world, but I would change this world for my child.



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## An Open Letter to the President & The President's Committee for People with Intellectual Disabilities (PCPID)

President Joseph R. Biden  
White House Domestic Policy Office, Director of Disability Policy Rachel Patterson  
Secretary of the U.S. Department of Health and Human Service Xavier Becerra  
Members of the President's Committee for People with Intellectual Disabilities, Jim Brett, Chair

Dear President Biden and all concerned,

This letter is written on behalf of the hundreds of thousands of individuals with intellectual disabilities and autism who are unable to speak for themselves, who rely on parents and siblings to speak for them. Many are non-verbal, while many others have speech but lack the capacity to make informed decisions that would ensure their own health and safety.

We comprise a large and varied cohort of individuals and families, and our voices need to be heard. We include the families of people who live their best lives in intermediate care facilities, who rely on high quality care that includes 24/7 nursing and active treatment, who are constantly threatened with closure of these facilities by legal actions from the DOJ, P&A, or the whims of a governor or state legislature. We include the families of people who have been denied care by group home providers who do not offer services and supports appropriate to our needs, or are unable or unwilling to deal with our loved ones' episodes of aggressive behavior. We include people who have been dual diagnosed with autism and severe mental illnesses, and reside in psychiatric hospitals because there are no services that meet our needs. We include family caregivers who want our loved ones at home with us, who cannot access the resources we have been promised, because of the shortage of Direct Support Professionals (DSPs) and the reluctance of many to deal with the challenges our loved ones pose. We include family caregivers who provided care at home because we cannot find appropriate placements for our loved ones in group homes or intermediate care facilities. We include people who have developed medical conditions as we have aged, and have been moved out of group homes that can no longer provide for our needs and have been moved into nursing homes. We include people who reside in prisons, because we were not provided with services that met our needs, and became a danger to society. We are individuals who have, for any number of reasons, not been granted the services that *we* need to live *our* best lives.

We have often been excluded from our own community. Many of those who seek inclusion in the community of non-disabled individuals often exclude those of us whose need services and supports not provided in community settings. People with mild to moderate autism, and the organizations that support them, opposed including the words "severe" or "profound" in the Autism CARES Act or the revised DSM-V. The last assembly of the PCPID considered phasing out sheltered workshops and 14(c) certificates, while excluding from its membership the families of those who benefit from working in those settings.

We fully support including people with I/DD and autism in all decisions made about their well-being. But "Nothing about us without us" has never included *us*, or our family members who speak for us, or the DSPs who work with us and care for us. "Nothing about us without us" does not allow those who know us best, who love us most, and who live every day fighting for us, to speak on our behalf.

*Our voices* need to be heard by the President, too. Any report from President's Committee for People with Intellectual Disabilities *must include us*, and our families and DSPs, so that the President is able to make fully informed decisions about programs that benefit *all* people with intellectual disabilities and autism.



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VOR is a national, non-profit 501(c)(3) volunteer organization speaking out for people with intellectual and developmental disabilities

**The VOR Voice – Autumn, 2024**  
**In this issue:**

- A Tribute to Larry Innis, VOR Treasurer
- Rhonda Butler and Derek
- Jill Clayton and Abby
- Abby Goldin's Page
- An Open Letter to President Biden & the President's Committee for People with Intellectual Disabilities (PCPID)

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Mail this form to: VOR, 836 S. Arlington Heights Rd. #351, Elk Grove Village, IL 60007  
Fax to: 877-866-8377 or donate online @ <http://www.vor.net/get-involved>

Thank you for your dues and contributions!

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- \$45 per year per individual;
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If the minimum dues requirement poses a financial difficulty, please contact our office in confidence (877-399-4867). It is in our best interest that you receive VOR's information. If you have included VOR in your estate planning, or establish a memorial fund, please contact us. If you would like additional information about your planned giving options, please call Hugo Dwyer at VOR, 646-387-2267 or [hdwyer@vor.net](mailto:hdwyer@vor.net).